

การพัฒนาศักยภาพด้านการวิจัยและจรรยาบรรณการวิจัยของอาจารย์ วันที่ ๒๒ พฤศจิกายน ๒๕๕๕

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## Researching Death and Dying

Presentation to  
Boromarajonani College of Nursing,  
Nakhon, Lampang  
Associate Professor Pamela van der Riet  
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## Factors that impact on the quality of end of life

Casey et al (2011)

- › Knowing the person and individualised care
- › Ethos of open communication between staff and patients about bad news, prognosis and treatment options
- › Culture, philosophy of the organisation of care
- › Multidisciplinary approach
- › Physical environment and resources

## Outline

- The importance of research in palliative care
- Factors that impact on the quality of end of life. A recent study
- Pamela's PhD storylines and discourses on death and dying
- Complementary therapies for end of life care
- Ethical issues in doing research on death and dying
- Challenges in researching end of life care

## Storylines and Discourses of dying

- › Emotional/ Psychological Discourses
- Feeling Threatened, Fear of Dying/Uncertainty, Shock, Loss and Concern for Children

- › *It is pretty frightening*
- › *for the kids to think*
- › *that they are going to lose their mum*
- ›
- › *That's how I feel*
- › *I felt threatened*
- › *to think*
- › *that the kids mightn't have a mother*

## The importance of research in palliative care

- › You might ask why research? Research is about improving practice and, therefore, producing good patient outcomes.
- › See podcast with Professor Margaret O'Connor Vivian Bullwinkle Chair in Palliative Care Nursing  
<http://www.youtube.com/watch?v=4weNYcpNwcM>

## Storylines and Discourses of dying

- › *'Cancer Means Death'*
- › *'I Just Accept Each Day as it Comes'*

## Emotional/ Psychological Discourses

### ► Hope

#### *'Keeping Going — Having a Goal'*

*My two goals.*

*are to see my eldest son's new baby.*

*and my daughter's wedding.*

*I think that is what keeps you going.*

## Emotional/ Psychological Discourses

### ► *'Some Forms of Death Worry Me'*

- I think people worry about
- that they will be alone
- that they will be in pain
- that they will be in a state of
- confusion
- or that they will be in a state of
- distress
- or that they will be in a state of
- despair
- or that they will be in a state of
- hopelessness
- or that they will be in a state of
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## Emotional/ Psychological Discourses

### ► *'It's Very Hard Watching Them Die'*

- The worst part is of course
- watching other people die
- and every one of them so quickly
- quickly, short
- it's very hard to watch
- them die
- it gets you down a bit
- But it's taught me so much
- it has taught me
- as from now
- not to fear
- death

## Emotional/ Psychological Discourses

### ► *Time to say goodbye to people*

- I suppose like most people
- I don't really look forward
- to a prolonged death
- Although I feel there is value
- in having a little time to die
- and people are aware of you dying.
- I think I would want
- I would want time to say goodbye to people
- I would like some time
- to explore my own dying
- Sudden death
- would be okay,
- but I'd rather have a little time
- to get used to dying
- I don't want to die alone either.

## Emotional/ Psychological Discourses

### ► *'The Quicker the Better'*

- *I just want to be comfortable and free of pain.*

## 'Holding On' and 'Letting Go' Discourses

- This holding on discourse often intersects with other nursing and medical discourses of dying.

## Spiritual Discourse

- › Easing into a Peaceful Death  
Massage  
Giving permission to die

## Ethics

- › Field of ethics is very broad
- › It covers the full expanse of thought and action directed toward answering the question, "What should I do?"  
(Komesaroff 2008, p. Xx iii)

## Data from Pamela's Phd

- After her visualization session Wendy moves about the soothing and relaxing effects
  - I enjoyed the neck
  - I like the feet too,
  - maybe more than the hands
  - That was a wonderful massage
  - I've been thinking about the rain forest, trees and waterfall
  - I felt the snow
  - Yes I went into the rain forest
  - That was lovely. I really enjoyed it.
  - Yes
  - I'm feeling relaxed
  - contented
  - nice and peaceful
  - Soothing
  - Just relaxed
  - no stress
  - I could drift off into the rain forest

## Attending to Relational Ethics

- 1.Procedural-mandated by the Research Ethics committees
- 2.Situational-refers to ethics in practice: unexpected, unpredictable situations, where researcher has little control over events (Goodwin et al., 2003)
- 3.Relational-recognizes and values mutual respect, dignity and connectedness between researcher and researched, and between researchers and the communities in which they live and work (Lincoln in Ellis, 2007)

## More data -After a massage and meditation session, Gary commented on the relaxation effects.

- What you are saying is very soothing
- Lovely, lovely you have got the voice and the tone and the right words
- You have used all the right words
- Very peaceful
- It just feels very relaxed
- You said take all the tension out
- There wasn't any tension to take out
- because you took it all out
- Yes. Just lying here my body could be elsewhere
- Just like floating on a cloud
- It feels very, very light
- My body just feels so relaxed.

## Responsibilities of the researcher

- › Need to Ensure:  
Participants' rights of autonomy choice, informed consent, lack of harm, confidentiality, anonymity respect and dignity are protected

(Seymour & Ingleton 1999)

## Reflexivity

- Researchers should subject themselves to the same level of scrutiny they direct towards their participants. How?
- Why did we choose to study what we study
- What is the problem to be explored?
- What are our assumptions?
- What are our expectations about our participants?
- Acknowledge how aspects of our identities (gender class) and how they affect data and the participants (McCorkel and Myers, 2003, Fonow and Cook, 1991, Hertz, 1997, and DeVault, 1995).

## Questions

## Ethical issues in researching death and dying

- ▶ Maintaining ethical conduct – talking about death
- ▶ Informed consent
- ▶ Recruitment of participants – gatekeepers
- ▶ Emotional challenges for the researcher
- ▶ Design needs to reflect core principles of palliative care

## References

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## Challenges in researching end of life care

- ▶ Difficulties in design
- ▶ Lack of agreed definitions of end of life care, palliative care
- ▶ Variable levels of awareness of diagnosis and prognosis in patients
- ▶ Difficulty in obtaining funds
- ▶ High attrition rates
- ▶ Managing the researcher's role
- ▶ Managing the emotions of participants, carers and researcher
- ▶ Inclusion approaches